



Carel, H. H. (2015). With bated breath: diagnosis of respiratory illness. *Perspectives in Biology and Medicine*, 58(1), 53–65.  
<https://doi.org/10.1353/pbm.2015.0013>

Publisher's PDF, also known as Version of record

Link to published version (if available):  
[10.1353/pbm.2015.0013](https://doi.org/10.1353/pbm.2015.0013)

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## With Bated Breath: diagnosis of respiratory illness

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Perspectives in Biology and Medicine, Volume 58, Number 1, Winter 2015,  
pp. 53-65 (Article)

Published by Johns Hopkins University Press

DOI: [10.1353/pbm.2015.0013](https://doi.org/10.1353/pbm.2015.0013)



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# WITH BATED BREATH

## *diagnosis of respiratory illness*

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HAVI CAREL

**ABSTRACT** This essay recounts the author's experience of diagnosis of a rare respiratory condition in order to invite a broader reflection on the nature of diagnosis. Diagnosis is a pivotal moment in one's illness experience, and it can be viewed as both a closure of possibilities and an opening of new, unanticipated ones. The notion of anticipation is also important to the illness experience, in that anticipation and waiting characterize the illness experience generally—in waiting rooms, anticipating test results—as well as the change in one's attitude towards the future, which becomes fearsome in illness.

### BROKEN BY BAD NEWS

I HAVE BEEN BREATHLESS FOR A LONG TIME. I lagged behind others when walking uphill. I became breathless when dancing. I couldn't play tennis. But I somehow convinced myself that this was normal. I was getting older—perhaps in one's mid-30s fitness drops like this, I thought? Perhaps I have “small lungs,” my husband speculated. But we were both physically active, and as we were living in Australia

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The author is grateful to the Wellcome Trust for its granting of a Senior Investigator Award. The research underpinning this paper was undertaken as part of the *Life of Breath* project, grant number 103340/Z/13/Z ([www.lifeofbreath.org](http://www.lifeofbreath.org)).

*Perspectives in Biology and Medicine*, volume 58, number 1 (winter 2015): 53–65.

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at the time, we enjoyed bush-walking, bike riding, and the sunshine that permeates outdoor life down under. So I masked my breathlessness as best I could, and never went to see a doctor, despite my clear and increasing respiratory difficulties.

Two years went by. We returned to live in the United Kingdom—in hilly Bristol, as opposed to flat Canberra. I remember having to pause to catch my breath as we were moving boxes to our tiny new flat on the top floor of a Victorian building. I tried to cycle to work but had to get off and push my bike, something I've rarely had to do before. It was Bristol's hills and my fast declining lung function that finally drove me to the doctor. I could no longer pretend everything was even remotely OK. The doctor asked me to blow into a spirometry tube, to measure how much air I could exhale. "My god," she exclaimed, "you have the lungs of a 60-year-old smoker! I've never seen anything like it." Her disbelief, on top of the worry that has by now become explicit and tangible, made me very anxious.

By that point, I knew something was seriously wrong with my breathing, and when I told my father who runs a medical screening center in Israel, he arranged for me to have a CT scan of my chest on my next visit. I was out in five minutes, feeling rather pleased that the scan was so quick, and went on to see friends in Tel Aviv. We sat on a café terrace and chatted and laughed. But in the back of my mind stayed the niggling worry about the scan results—what would they reveal?

I met up with my parents later that day, and as we drove home, we passed the medical center. My father said he was going in to collect the scan results and that he would be back in five minutes. My mother and I waited in the car. The five minutes turned into 10, and the 10 to 15. By then, I was overwhelmed by a sense of doom, by a very clear sense that my worst nightmares were coming true and something horrific was about to unfold. Feelings of anticipation, anxiety, hope, and dread intermingled, making that interval a long and memorable stretch of time.

After a further while passed, I told my mother I was going to find my dad. I marched into the x-ray department, pushed past two nurses, and burst into the radiologist's office, which was dark, with the blinds drawn to better see the computerized images on the screen. Right before me, on the screen, glowed an image: a reticular structure, much of it filled with black holes and traced with white lines. My lungs. The radiologist saw me come in and laughed an artificial, awkward laugh: "Ah, so you're the patient. Let me show you what you've got." I was somehow seated, and a heavy book—a diagnostic manual—was placed in my lap, open to a certain page. A long word glared back at me: *lymphangioleiomyomatosis*. I stared at the page, skimming the sparse information on it; I didn't know what the medical terms meant. I just knew it was something serious, and that the weight of the book resting on my lap symbolized the weighty diagnosis it bore, about to change my life. Nothing will ever be the same, I thought. Once I read this page, everything is going to change. I somehow knew what I refused to know before: that I was seriously ill and now was going to discover what my illness was. I skimmed the text, dense, medical, and officious. At the bottom of the page, a sentence read: "Prognosis: ten

years from onset of respiratory symptoms.” Ten years, I thought to myself. I will die before I am 45.

This was the stuff of fairy tales and myths. There I was, reading a book telling me about my own impending death. The diagnostic manual was my personal book of prophecy. I was to have my endpoint revealed to me. The oddness of this struck me. The future was being unveiled to me with nauseating clarity by this very book and the diagnosis it contains. But this wasn’t supposed to happen in real life: clairvoyants exist only in fiction. Suddenly, my radiologist became a clairvoyant, and my life became a story whose plot has gone awry.

Around me medical work continued, albeit under the shadow of my unwanted presence. Words were flung back and forth, people shuffled uncomfortably. A young medical note-taker offered faint solace. I tried to find something to say. My father stared at the screen, head resting on his hands. His childlike, bewildered pose was frozen, fixated on the glowing image of lungs: full of holes, hyperinflated, damaged. My lungs. Irreparably damaged—but I did not know that then.

A sudden flash of pragmatism flooded me. “OK, so what do I do?” I asked the radiologist. I imagined a tough course of radiotherapy, perhaps some medication or a diet, a strict exercise regime. I braced myself for the worst, most painful and exacting treatment. But nothing prepared me for his reply: “I only diagnose, I don’t treat,” he said evasively. I realized, without anyone saying it, that my illness was more serious than I thought and that it had no treatment. That possibility has never occurred to me, with my naïve untested faith in modern medicine and my lack of past experience of any serious health problem. The point of diagnosis was also the point of prognosis for me. And neither was very good. Those people in the room didn’t want to—but had to—tell me what I “had.” Their discomfort was palpable. My shock was complete. An invisible line descended upon us and divided the room into the healthy—the lucky, the temporarily amnestied—and me, the ill person, bereft and alone.

I sat there for some time, while the radiologist continued to point out various features of my lungs on the screen. The note-takers sat quietly. My father was stunned. No one spoke to me. It was at that moment, I now realize, that I became “a patient.” The object of medical inquiry, but also an object—a physical entity with certain features and pathologies that can be understood via molecular processes, signaling pathways, symptoms. My speech would become “a patient report.” I would be a name on a waiting list, a file in a trolley. And eventually, a body in a hospital bed.

The reduction was instant and dramatic. I was no longer a person, the daughter of the medical director, a woman in distress. I was a diseased body who—inconveniently, embarrassingly—belonged to that woman, that daughter. The radiologist had a tough time delivering bad news to a colleague. He had a tough time delivering bad news to a patient—not something he routinely does. His usual role—analyzing computerized, disembodied images stripped of identity and life—was upset by the unusual scene. I wasn’t meant to be there. And hence, I was absented from the scene despite my physical presence.

Instinctively I sought to reclaim my subjectivity, my personhood. I needed to be re-anchored in the intersubjective world from which I was unceremoniously and silently exiled. I looked up from the book and said the only thing that came into my mind: “Can someone call my mother?”

I walked out of that room a changed person. I know people were staring as I was led out, a parent on each side, crying. I noticed the stares but I didn’t care. I was engulfed by sorrow, consumed by disaster, traumatized. I was terribly sick. My disease was rare and no one knew how to treat it. I would die within 10 years. How was I supposed to live on with the knowledge of my diagnosis and the grim prognosis? How was I supposed to drive home, eat dinner, sleep, shower, talk, do all the normal things that normal people do, when my very own body was a time-bomb tick-tocking my life away? Somehow the duration—10 years—and my associated helplessness, despair, and fear made those 10 years not worth living, or more accurately, impossible to live.

It took me a long while to progress beyond this primal scene of traumatic diagnosis. It wasn’t supposed to be like this, I now know. Medics are specially trained in “breaking bad news”; they practice and role play and prepare themselves for a moment of solicitude, empathy, and support. They ordinarily have time to prepare themselves and rehearse their words prior to meeting a patient. I just barged in. I should not have been there. My diagnosis was outside the protocol. It was a rogue event, in another country, with the added complication of my father’s collegial relationship with the radiologist. My thoughts turned to the mechanics of that medical center.

The medical screening center was a tightly run ship, where reports were efficiently filed and letters promptly checked and sent out. Letters containing bad news, threatening to curtail lives, announcing the advent of pain, suffering, incurable illness. My father was proud of the center and of how polite, prompt, and efficient its staff and processes were. But the smooth machinations of that medical center stood still at those moments when health professionals were caught between two beliefs: the tacit, naïve belief that they were diagnosing *other* people, and the realization that the diagnoses being churned out through a sophisticated chain of diagnostic tests, their interpretations, and their clinical import, might suddenly turn self-referential. The emperor’s daughter had no clothes, no protection, from the vagaries of ill health.

That evening and the following days were a hallucinatory haze of hysterical laughter, panic at the thought of facing the inevitable internet searches, and a new sense of bodily fragility. Friends rallied round, asking questions, talking animatedly, offering hugs. But I was too fractured, too shell-shocked to be able to use that support. I didn’t want to talk to anyone, but I needed the solicitous, yet silent, company of others. I stayed in limbo, in my parents’ home, in my old bedroom, for several weeks. How could I fly, having learned about the risks of lung collapse in air travel, let alone resume a life of some resemblance to the one I had before? Going back to my flat and job in England seemed out of the question. Doing anything

seemed out of the question. I was suspended in mid-air, reading novels, lying low, licking my psychological wounds. For me, diagnosis was a break with all that came before it. It shattered a life and altered its course in unprecedented ways. I knew I somehow had to forge a way forward from this impasse, that the sunshine and novels were going to run out and that my life had to resume from its forced, violent pause, in some way. What I didn't know was how.

### **WAITING FOR A DIAGNOSIS: FETAL ALCOHOL SPECTRUM DISORDER**

Waiting for a diagnosis was, in my case, a very short wait. In just one day I moved from being worried but healthy to having a confirmed diagnosis of lymphangioleiomyomatosis, or LAM. This is unusual. More commonly diagnosis is a much more protracted, confusing, ambiguous process punctuated with variable periods of waiting for particular diagnostic tests, test results, medical appointments, and treatment decisions. In this section, I contrast my instant LAM diagnosis with a diametrically opposed experience of a slow process leading to diagnosis: that of fetal alcohol spectrum disorder (FASD) in a child. FASD affects as many as two to five people in 100, and it is a lifelong condition causing severe physical and mental disability and social, educational, and adaptive deficits (May 2009). Prenatal alcohol exposure damages brain development, causing deficits in executive and cognitive function characterized by inattention, hyperactivity, impulsivity, hypervigilance, and poor adaptive behavior. It may also cause a range of physical disabilities and problems.

Despite its high incidence, its tremendous impact on children, their families, and those around them, and the fact that it is 100% preventable, FASD remains largely unknown, and drinking in pregnancy remains socially acceptable in many countries (Carpenter, Blackburn, and Egerton 2014). Although it is common, FASD is poorly recognized by both the general population and by pediatricians and child psychiatrists, the specialists who would be consulted about the presenting symptoms (Frances 2014). It is also (partly because of its relative anonymity) notoriously hard to diagnose (Blackburn 2014). Only a handful of specialist clinics can confidently give a diagnosis of FASD. So how would the diagnosis process unfold in this case?

The child may initially present as hyperactive, impulsive, and disruptive, but possibly also as hypervigilant and often with impaired social relations. She may be given a wrong diagnosis of ADHD, or if she has come through the care system (removed from birth family, placed in a foster home, and then placed for adoption or long-term fostering), she may be diagnosed as having attachment disorder. The presentation for all three conditions can be very similar and may also overlap with some genetic disorders, such as fragile X, or psychiatric disorders, such as oppositional defiant disorder (ODD). A lengthy investigative process may ensue, requiring assessment by several health and education professionals: educational

psychologist, occupational therapist, neurologist, pediatrician, child psychiatrist, speech and language therapist, and general practitioner. These consultations and assessments may take place over many months, more usually years. And sometimes at the end evidence will be too inconclusive to secure a diagnosis. The child in the meantime may be moved out of mainstream education and later on become vulnerable to delinquency, social isolation, dropping out of education, and family breakdown. Many social and educational opportunities may be lost, as well as points for potentially useful intervention, because of the lack of diagnosis or misdiagnosis.

This example ties in with the many stories of people who describe how, for years, they complained of individual symptoms that did not add up to a clear clinical picture, so that their conditions remained undiagnosed. In such cases, the plight of the ill person is exacerbated by the uncertainty about the meaning of the symptoms. It also means that the ill person will not have access to the best available care, and will be cut off from the advocacy and support of the relevant patient groups.

The period before the correct diagnosis is given is characterized by waiting and anticipation. Think of the FASD child prior to diagnosis. She will be seen by a host of specialists, the family will have been waiting for appointments, reports, phone calls, and letters, for answers and information, for a response to a medication, for test results—the list goes on. These concrete acts of waiting give rise to a mode of existence characterized by anticipation—of the next step in the medical story, of the moment at which a conclusive diagnosis will be given, of the unfolding of an uncertain, sometimes frightening, future. While this form of existence as anticipation characterizes “patience” in all its stages, it is particularly accentuated in cases where investigations and concerns are ongoing and a diagnosis is delayed, such as the FASD case described above.

Anticipation is the state of awaiting a future event. The event may be certain or just possible, fixed in time, or undetermined. It may be welcome or unwelcome, bringing joy or anxiety. In short, anticipation is the temporal structure of intending towards the future, with the exact properties of the event inflecting the anticipation. The anticipation of a visit to the dentist may be very different to another kind of anticipation—say, of going into labor. Although giving birth may be much more painful than a dental procedure, the intending towards it is usually also tinged with excitement and positivity, so the pain dimension becomes contextualized and is less important.

However, like the underlying health condition being investigated, anticipation can also become chronic, exhausting, and crippling. For example, women with ovarian cancer report being paralyzed by the fear of recurrent disease and live from one check-up to the next. According to V. Jayde (2014): “women’s fear of recurrence was experienced as a very deep and omnipresent menace—a ‘shadow’ cast over their efforts to resume a normal existence” (193). The temporal experience in such a situation will also be different: this is a life lived in installments, from one check-up to the next. The future ceases to flow as one organic unit and instead becomes



chopped into small units of “future allowed.” Thinking beyond these time units would be hubristic, so patients consign themselves to the permissible future, treading with care, one day at a time: “For most women, the plan-able future stretched as far as their next follow-up appointment and no further . . . . Whilst few women spoke of future goals, several described actively anticipating their future, including their possible ovarian cancer-related death” (196). Jayde describes how for these women “the time of transition was experienced as ‘hiatus’ between the cancer and their [sic] likely recurrence and subsequent death” (196).

This example reveals another aspect of anticipation: it is enmeshed with a sense of fragility and loss. The loss of bodily certainty and of wholeness, certainty, control, freedom to act, and the familiar world are played out in anticipation (Carel 2013; Toombs 1992). Simple routines take longer to perform and sometimes become impossible; choices are curtailed by limitations, which also constrain the kind of things one can anticipate; and dread about the future may amplify the sense of fragility, vulnerability, and dependency that characterizes illness (Carel 2015).

Anticipation, waiting, and the state of being a patient are interlinked and affect the ill person’s experience of time; this is exacerbated when diagnosis is delayed. In the following sections I suggest that the process of waiting for a diagnosis and the ensuing diagnosis itself involve both a closure of possibilities as well as an opening up of new and unanticipated possibilities. Diagnosis, like illness, may have some positive elements in it, although these are usually unintended, unanticipated, and surprising.

### DIAGNOSIS AS CLOSURE OF POSSIBILITIES

My diagnosis took place in April 2006. Now, almost 10 years later, the prophecy still hangs over me. I still have a sense of a great rift between the person who walked into that medical center on that afternoon, and the one who walked out in tears, supported by her parents on either side. In one respect, the change was immediate: the transition to becoming a patient took place while I was still in the radiologist’s office. But in other respects it extended over time. With time, my illness progressed, I became savvy about hospital appointments, blood tests, and dealing with the daily mechanics of being ill. I developed deep links with some health professionals who have now looked after me for a long while. And I incorporated the experience of illness into my academic work and writing (Carel 2013). My illness has become enmeshed with my and my family’s life in deep and restrictive ways.

So how does a patient navigate a trajectory which begins with symptoms, usually followed by diagnosis, prognosis, and then disease progression or treatment, and sometimes recovery? Can we point to a “form of life” that characterizes this trajectory?

The act of diagnosis is, as Suzanne Fleischmann writes, one “fraught with symbolism”: the delivery of a diagnosis “serves to divide a life into ‘before’ and ‘after,’

and this division is henceforth superimposed onto every rewrite of the individual's life story" (qtd. in Jutel 2011, 2). The time of symptom appearance, prior to diagnosis but also after, is a time of great change and the upsetting of previous life habits. Small things like running for the bus or taking stairs two at a time become the stuff of fantasy for a respiratory patient: although minor, they become things the ill person watches others do with awe. But after diagnosis, even the envy patients previously felt while watching others do things they could no longer do disappears: those things are no longer live possibilities for the ill person. I suggest that the most immediate experience that follows diagnosis is a loss of freedom in the broadest sense. More than anything, diagnosis announces illness, which is the loss of opportunities, possibilities, and openness. It is the closure of a previously open future. It is also the closure of the present: current daily activities lose their casual aspect and become demanding projects. What could once be done unthinkingly is now an explicit task, requiring thought, attention, and a pronounced effort.

Diagnosis signals a move towards turning symptoms into a less subjective entity. They are now organized in an explanatory pattern that excuses, explains, and predicts illness behavior. In this sense, diagnosis can be experienced as an affirmation of subjectively experienced symptoms, making one not "just a complainer" but someone who has a genuine medical condition justifying certain adjustments. For example, many women presenting with breathlessness due to LAM (which only affects women) are diagnosed as having some form of anxiety, panic attacks, or other psychological disturbance. When the correct diagnosis is made, a woman may feel vindicated that her complaints were not just figments of her imagination but a "real disease."

But the diagnosis also signals an appropriation of the individual's pain by the other's point of view. Jean-Paul Sartre (1943) writes:

At this point a new layer of existence appears: we have surpassed the lived pain toward the suffered illness; now we surpass the illness toward the Disease . . . . It is then objectively discernible for Others. Others have informed me of it, Others can diagnose it; it is present for Others even though I am not conscious of it. Its true nature is therefore pure and simple being-for-others. (379–80)

The diagnosis marks the time in which the illness (the ill person's subjective experience of her ill body) becomes known by others and by the ill person *as disease* (the objective process causing the illness). It becomes objective (or objectified) and subjected to medical management, labeling, and so on. This transition from a private, subjective experience to an objectified disease, which continues to be experienced as illness by the ill person, is significant. The illness is no longer a private musing on the nature of bodily change, but an item in a medical vocabulary and ontology, to which shared meanings and knowledge are attached. One's hospital file, pushed around on a little trolley, exemplifies the appropriation of illness by disease. The file contains test results, letters to and from specialists, and requests for further tests,

but nothing else. It is a file *about* the patient, but not *of* her. That file symbolizes the subsuming of breathlessness, pain, suffering, social awkwardness, sense of bodily failure, and fear of death, under a medical description. And under that aspect, the lived correlates of the medical information are often relegated to the “subjective-and-hence-secondary” pile.

This transition towards a formal medical diagnosis and the accompanying labeling can bring with it great relief. The sense of having an objective and known condition releases at least some of the sense of shame, guilt, and inadequacy that may characterize earlier stages of symptom experience. When the symptoms come together to form a clear and objectively recognized picture of a particular disease, certain social changes ensue: the ill person is now recognized as deserving special consideration, societal resources may be mobilized, and the patient may assume the “sick role” and conform to its unwritten rules (Parsons 1971).

But the changes can also be negative. Ill persons may feel a loss of control and loss of continuity with their previous selves. They may feel that the disease has taken over their identity and life course and that they are therefore helpless and mired in uncertainty. The limitations brought about by the disease may also become clearer through further medical information, contact with other patients in more advanced stages of the disease (if it is progressive), and a prognosis. The limitations can be thought of in terms of closed possibilities—the illness may bring with it limited mobility, reduced energy levels, pain or incontinence, physical constraints, or other limitations. As these become apparent and ordered around the diagnosed disease, an increased sense of incapacitation and limitation may become the dominant experience. Echoing Husserl, A. Kesselring (1990) describes illness as a move from “I can” to “I used to be able to, but I no longer can.” A list of things given up may become ever longer as time goes by, cementing the sense of closure. This was, for a time, the paradigm in descriptions of illness: loss, the breaking of identity, disruption of narrative, and disruption of lived experience. However, diagnosis also opens up possibilities for future-directed thinking and living in the present. It is to these that I now turn.

### DIAGNOSIS AS OPENING POSSIBILITIES

So far we have looked at illness as an external intrusion, manifesting initially as unexplained symptoms that transform after diagnosis into a more understandable cluster, that forms a particular disease. In this section of the paper I suggest that the potential of diagnosis to open up new possibilities is great, but it has not been articulated.

In order to work out the positive potential impact of a diagnosis, I’d like to return to the FASD example. First, on a practical level, a correct diagnosis opens the way to the best available treatment. A child affected by FASD who was previously labeled as “naughty,” “antisocial,” or “defiant” now has a medical diagnosis that obliterates the connotations of personal failure. The child is not morally suspect, or of flawed

character, but suffers from a medical condition that causes him or her to behave in ways that are socially unacceptable. The behaviors may still be perceived negatively, but having an explanation in the form of a medical diagnosis lessens the negativity with which the child is perceived.

Second, the diagnosis triggers a host of actions from a range of health and education specialists. The diagnosis may be used to access a range of health, education, and social care services that will be coherently packaged and tailored to the child's needs. (In the United Kingdom, this is now known as an "educational and health care plan," or EHCP.)

Third, the diagnosis provides psychological and explanatory stability to the adults involved in caring for the child and, in time, also for the child itself. It can serve to underpin attitudes towards the child, so that the child's behavior is seen as a result of disability ("she can't follow instructions"), rather than of willful defiance ("he won't follow instructions"). This can enable parents to parent better and more patiently, and other adults to accept the functional limitations and special needs of the child.

Fourth, the diagnosis opens the way to connecting with others suffering from the same condition and to benefiting both emotionally and practically from their experience, advice, and practical knowledge. Other "patient experts" may not only share knowledge about the medical aspects of the condition, but they may also offer support with navigating the health and social care systems, identifying specialist local services and charities, and providing practical tips on disease management. Connections with other patients or carers, in the form of online fora, local support groups, or specialized charities or other services (such as post-adoption support for adoptive families with children suffering from FASD), can provide ongoing and substantial support of various kinds, ranging widely and provided locally.

Finally, on a more philosophical level, illness has been compared to other traumatic life events that can lead to "posttraumatic growth" (Haidt 2006). This phenomenon is key to a more positive understanding of diagnosis, and so is worth expanding on. Jonathan Haidt's hypothesis is that we are more resilient than we think: we erroneously believe that adverse life events, such as serious illness, accidents, divorce, or the loss of a loved one, will affect us more intensely and for longer than they actually do (see also Gilbert 2006; Lyubomirsky 2007).

According to Haidt, people systematically underestimate their ability to cope with adverse circumstances and have no way of predicting the personal growth, resilience and development that often follow a period of great difficulty. He presents an "adversity hypothesis": "people need adversity, setbacks, and perhaps even trauma to reach the highest levels of strength, fulfilment, and personal development" (136). Haidt calls this consequence of experiencing adversity "posttraumatic growth," and he identifies three mechanisms that enable such personal growth in the face of adversity.

First, Haidt observes, confronting a challenge in the form of an accident, divorce, losing one's job, or an illness reveals hidden abilities that change one's self-image:

“One of the most common lessons people draw from bereavement or trauma is that they are much stronger than they realized, and this new appreciation of their strength then gives them confidence to face future challenges” (139). This is not just a form of self-deception: studies show that people who have suffered hardship recover more quickly when faced with future adversity—they have genuinely become more resilient. And this notion tallies with the view of suffering as morally or spiritually beneficial and edifying (Kidd 2012). Suffering can be mitigated by a deep sense that it is aimed at some end, and that it has meaning—in other words, that it is a trial, a journey, or a lesson, some of the common metaphors used to describe illness. This would be true whether or not the suffering actually was edifying or purposeful, since the very belief that it is could be positively motivating. For example, the pain of childbirth is often described as being mitigated or interpreted very differently from other kinds of pain because of its productive and life-bestowing purpose (Heyes 2012).

The second mechanism is the improvement to relationships that is often noted in circumstances in which people are forced to speak frankly about important issues, such as death and disease, and are forced to ask for help from family and friends. The lack of intimacy that characterizes many routine social encounters becomes untenable, and an opportunity emerges for authentic relationships to become stronger, and for honesty and intimacy to be sought with clarity and intensity. As Bronnie Ware (2012), a palliative care nurse, writes about caring for a dying woman: “once we reached this level of honesty, our conversations flowed unhindered. There was no time for holding back. . . . With death on her doorstep, Elisabeth, too, enjoyed the openness of our constant exchanges” (149). The actor Christopher Reeve, who became paralyzed from the neck down in a sports accident, famously said that he did not appreciate other people nearly as much as he did when severely disabled (qtd. in Gilbert 2006). When adversity strikes, Haidt notes, it “strengthens relationships and opens people’s hearts to one another” (139).

The third mechanism is a change of priorities and values, during which people who undergo adversity increasingly focus on the present. This has been noted in many qualitative studies of people who have become ill (see, for example, Brennan 2012; Frank 1991). The unpredictability of the course of illness leads some to adopt a perspective of living in the present and refraining from looking towards the future, making long-term plans, or having rigid goals (Carel 2013; Michael 1996). One of the reported changes to their lives in this refocusing on the present is that it leads to greater enjoyment of and attention to one’s current experience. In the case of illness in particular, because of physical and mental limitations, pain, limited mobility, fatigue and sometimes a poor prognosis, the emphasis on what is still possible to enjoy is often described by ill people as a positive way of dealing with the effects of illness. But this is not something that happens automatically; it is the result of a long process of adjustment and reflection.

## CONCLUSION

This paper offers a firsthand account of diagnosis. Although in some respects my experience is atypical, because of the rareness of the condition and the informal circumstances in which my diagnosis took place, it is nonetheless phenomenologically illuminating. Between the two extremes of my case and the hypothetical case of FASD lie a spectrum of diagnosis processes and their accompanying experiences. It is important to keep sight of the diversity of experiences and meanings of diagnosis in order to escape both the Scylla of social scripting and the Charybdis of medical reduction that threatens to impoverish illness and diagnosis accounts.

Diagnosis represents both a closure of possibilities and an opening of possibilities. It is a closure of openness and freedom and, in cases of poor prognosis, also a temporal closure. But it may also open possibilities for well-being, intimacy, and posttraumatic growth in surprising and often overlooked ways. This account of closure and opening allows us to understand the many reactions to serious diagnosis, which can range from depression to denial.

I close with a suggestion. The process of adjustment and reflection in response to a diagnosis of an illness can also trigger philosophical reflection, and this may have a further, unanticipated positive consequence. A diagnosis is the kind of shock that forces ill persons and their families to reflect and to make decisions and sometimes far-reaching changes to how they live, what they want out of life, and how they pursue their goals (Carel 2014).

The philosopher Maurice Merleau-Ponty (1945) has likened illness to “a complete form of existence” (110). In a similar vein, Merleau-Ponty’s contemporary, the medic and philosopher of science Georges Canguilhem (1966), has defined disease as “a new way of life for the organism,” the creation of new norms that govern the relationship of the diseased organism to its environment (84). I suggest that diagnosis is part of the process of creating a new form of life for the ill person, and as such it contains a productive and surprising host of positive consequences that are impossible to anticipate but that provide a much-needed antidote to the overwhelmingly negative experience of receiving a diagnosis.

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